Quality of life in epilepsy

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Quality of Life in Epilepsy: Multidimensional Profile and Underlying Latent Dimensions

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Part of our study, the ***Du*tch *Q*uality of Life and *Q*uality of Care *I*nvestigation in *E*pilepsy (*DUQQIE*), intended to cover several of the components of the quality of life (QoL) concept. To this end, a series of already existing generic and disease-specific instruments was selected covering several parts of the QoL components in order to construct a multidimensional ''QoL profile'' for people with epilepsy and to look for underlying second-order QoL dimensions. From the records of four outpatient clinics, 210 persons with epilepsy were randomly selected. During their visit to the outpatient clinic, they completed a questionnaire assessing, among others, health perceptions, psychological well-being, and social functioning. Additional information about their medical and psycho–social status was gathered from the patient files. A large part of our research group was not seizure-free. As far as comparisons with other patient or healthy groups could be made, it appeared that they mostly did not (much) worse and all scores were above the scale midpoint. However, almost two-thirds of the scale means lied below a so-called ''normative mean.'' Higher-order factor analysis yielded one general factor measuring the ''Overall Quality of Life.'' Furthermore, after rotation of this general factor, two separate factors could be constructed referring to the psycho–physical and psycho–social aspects of QoL, respectively. We decided not to develop ''quality of life instrument'' de novo to the already vast and ever increasing area of QoL instruments, but to use already existing, mostly generic, and well-validated instruments. The most important advantage of this approach is that it allows for ''normative controls'' (norms; other groups) and ''conceptual modeling.'' The latter is that the QoL concept can be unfolded into its component parts and hypothetically related to each other. **Key Words:** Quality of life—Profile—Epilepsy—Adults.

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Quality of life (QoL) is a widely used concept often referred to as ''health related quality of life'' (HRQL) as far as QoL is related to the consequences of disease and medical interventions (1–3). Although the concept is widely known, it may, however, mean different things to different people (3–6). The ideas about the concept of QoL have strongly been influenced by the WHO definition of health (7), and generally one agrees about the idea that clinical data only do not suffice to carefully evaluate and understand the consequences of chronic illness and medical interventions for the QoL of the persons involved. In case of a chronic condition, the life-style of affected individuals may be strongly disrupted, ''…interfering with continued involvements in valued activities and interests, and compromising quality of life'' (8). Adjustment to a chronic illness, such as epilepsy, is not merely a function of the severity or duration of the disorder. Responses from the family and other significant others may be more menacing than the illness itself (9–12). Since the consequences are much far-reaching than only the physical aspect (i.e., seizures), a broad approach of the conceptualization and assessment of QoL in epilepsy is often strongly being advocated and should contain not only the assessment and evaluation of seizures, but also other life domains such as cognitive and emotional functioning, role activities and social functioning, health perceptions, and general satisfaction with life (3,6,13). A chronic illness may not only mean a gradual deterioration of the body but, as a consequence, also of one's self-concept and social relationships (14–16).

In a medical–sociological model, the patient's experience of illness is emphasized and it is concerned with how understandings of illness may vary (17). As Devinsky and Cramer (18) stated: ''The patient is the only one who knows how he or she feels, how the disorder affects that person's vigour, self-confidence, ability to socialize, obtain work, and function at home and on the job. Surely, the patient's reports may be biased, as may be the doctor's. However, the patient is the person who must define his own quality of life …Only the patient knows if an imbalance exists between expectations and reality…'' (19). This corresponds to the WHOQOL-group definition of quality of life: ''individuals' perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards, and concerns'' (19). On the basis of these considerations, we took the patient's perspective on QoL as our starting point in our study ''The *Du*tch *Q*uality of Care and *Q*uality of Life *I*nventory for *E*pilepsy'' (*DUQQIE*).

Quality of Life: Levels and Measurement

Spilker (20) claims that QoL must be viewed on three levels (Fig. 1). Level one contains the overall assessment of QoL and is defined as ''an individual's overall satisfaction with life, and one's general sense of personal well-being'' (21). This is also often referred to as ''clinical global impression,'' a question that can ''…be best answered by the patient and not by the physician'' (20). The second level comprises the major domains of QoL the physical, mental, and social domain (including social–economic aspects such as occupational role and academic achievements) (20,22). The third level includes specific aspects of each domain. The model assumes that lower level variables or aspects determine the more general valuations on a higher level and ultimately the ''overall assessment of well-being.''

Another important issue is the question of which type of measure should be used: a *disease-specific* measure or a *generic* measure (1,23,24). If one's aim is to assess similarities and dissimilarities of psychosocial consequences across chronic illnesses, generic measures should be chosen [''noncategorical approach'' to chronic disorders (25–32)]. Moreover, only these latter measures allow for studying the cause-and-effect patterns between QoL dimensions or aspects across disorders. If one wishes to collect additional information on specific aspects of a particular disorder, supplementary ''disease-specific'' measures may be added (28).

The short-term aim of this article (i.e., the research questions to be addressed) is to find out what the QoL of our adult respondents looks like. More specific: first, to give a description of the QoL profile of the respondents of our research group and the procedures used to construct such a profile; second, to compare our findings to those of other studies (specific groups and ''normative data''); and third, to explore the feasibility and usefulness to construct more overall QoL measures based on dimension-specific measures. The long-term aim of our study would be to get an insight in and explanation of (dis)similarities in QoL aspects across diseases and healthy populations. Such a long-term aim can only be achieved by carefully comparing outcomes of studies, using similar generic measures among samples consisting of people with various chronic disorders.

Table 1. *Educational level and employment status (in percentages)*

Education Level		Employment Status	
Primary education	3	Full-time job	21
Lower vocational	56	Part-time job	14
Lower secondary	22	Sheltered workshop	12
Middle secondary/vocational	18	Disablement pension	24
Higher vocational/university	1	Unemployed	4
		Retired	2
		Housewife	16
		Full-time education	7

Materials and Methods

Sample

Patients were selected from outpatient clinics of the Department of Neurology of the University Hospital in Groningen and of the special epilepsy centre ''Meer en Bosch'' in Heemstede, in total four outpatients clinics, all in the northern region of The Netherlands. Patients who came for an appointment with their neurologist, were eligible for enrollment into the study. To be included in/excluded from our study the following criteria were used: (1) inclusion criteria: ages from 18–65 years, and a definite diagnosis of epilepsy; (2) exclusion criteria: malign epilepsy syndromes accompanied by a mental handicap or the presence of sever psychiatric disturbances as reflected in an earlier psychiatric admission. Of the 275 patients with epilepsy who all fulfilled these inclusion and exclusion criteria for enrollment in the study, 225 (82%) participated. Because of missing data or unclear answers, 210 persons were used in the final analyses.

The patients were asked to fill out a questionnaire at the same day they visited their neurologist at the outpatient department. During this session they were supervised by the research assistant. In addition, the research assistant collected demographic and clinical data by means of both a short interview with the patients and information from their medical files. A letter of informed consent, signed by the patients, was obtained from all the subjects participation in the study.

Composition of the Research Group

Nonclinical Data

Of the 210 respondents, 51% were men and 49% women. The mean age was 38 years (sd = 11.4). Sixty-six percent was married, a high percentage as compared to the result of some other recent studies (33,34). Approximately 30% was a member of the Epilepsie Vereniging Nederland (EVN) which is the Dutch patient organization for patients with epilepsy, their parents, or partners. This percentage is about 10 times as high as the corresponding percentage for the total group of people with epilepsy.

As compared to the Dutch population (35), the educational level* of our group was generally below average: 81% had only lower types of education as opposed to 19% with a higher level of education. Consequently, the employment status was rather low: only 35% had paid jobs (Table 1).

Clinical Data

An overview of the clinical data is presented in Table 2. Seventy-eight percent of our respondents had an onset of epilepsy before the age of 21 years. Furthermore, 12% had a generalized type of epilepsy: 10% idiopathic and 2% symptomatic. As much as 81% of our respondents had partial epilepsy. Consequently, complex partial seizures were most frequently encountered (Fig. 1).

The rather high percentage of partial epilepsy may be a consequence of the composition of the population from which we drew our sample (36), the enrollment procedures used in our research, and/or from the increasing possibilities of the electroencephalogram (EEG) techniques and other neuroimaging technique that more often than before allow for the assessment of an epi-

*From 36 persons also the IQ was available. From this it appeared that their IQ was average (mean IQ = 101.6; sd = 14.1). This might perhaps indicate that our respondents do dispose of adequate intellectual capacities and that the achieved level of education would be more in agreement with their capacities if they were not hindered to do so because of an early onset of their epilepsy.

Table 2. *Clinical data*

Mean age of onset	15 years (sd = 11.0)
Percentage onset before 21 years	78%
Mean duration	23 years (sd = 12.3)
Unknown etiology	87%
Generalized type of epilepsy	12%
Partial epilepsy	81%
Unclassifiable type of epilepsy	7%

leptic focus (37,38). We will shortly return to this issue in the Discussion section. Twenty patients were seizure-free for at least 1 year. However, most respondents (59%) still had regular seizures. In 6%, a status epilepticus occurred. Seventy-one percent used two or more antiepileptic drugs (AEDs), with carbamazapine and sodium valproat most frequently used.

Measures and Analyses

Referring to our former discussion and the three-level model of Spilker, we decided not to develop QoL/HRQL measures de novo, but to look for a number of overall, domain-specific, and dimension-specific generic instruments that (1) according to Spilker's conceptual model, discussed earlier, cover both the general health perceptions and adjustment, and different aspects of physical, mental, and social functioning; (2) that enable comparisons to be made with some previous studies on QoL and epilepsy; (3) that enable comparisons to be made with other studies on QoL, both among samples of people with other chronic conditions and among healthy populations (''normative data''); (4) that for the greater part have proven their reliability and validity; and, (5) measures/instruments of which, besides a Dutch version, also other language modules (e.g., an English and German version) are available for reasons of comparisons with previous studies as well as because of intended, planned international research.

In our study we used 13 QoL measures. Five of them were not generic (i.e., in the items of these measures the word ''epilepsy'' was used). However, the word ''epilepsy'' can simply be replaced by another chronic condition. Indeed, several of these measures have been developed in studies among samples with another chronic illness such as rheumatoid arthritis (RA) and multiple sclerosis (MS) (see below). Although these measures are

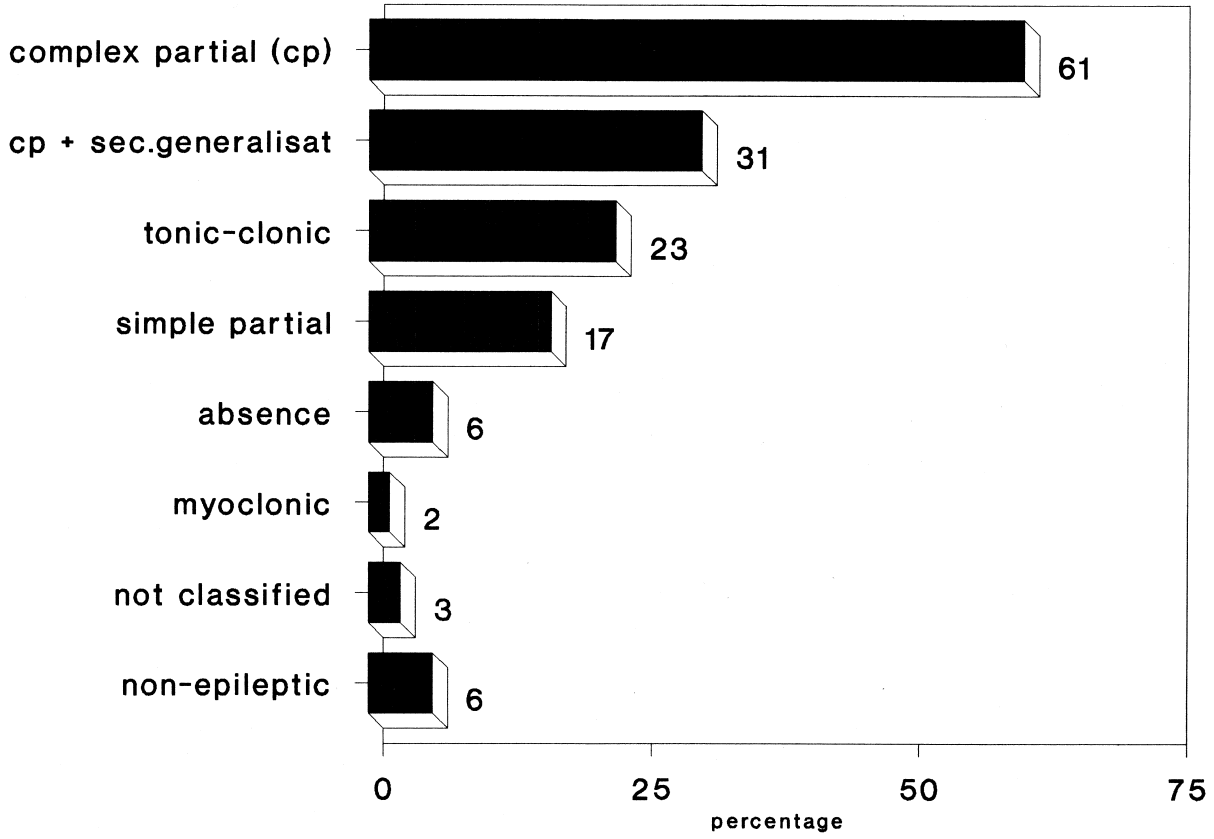

Figure 1. *Frequency of seizure types.*

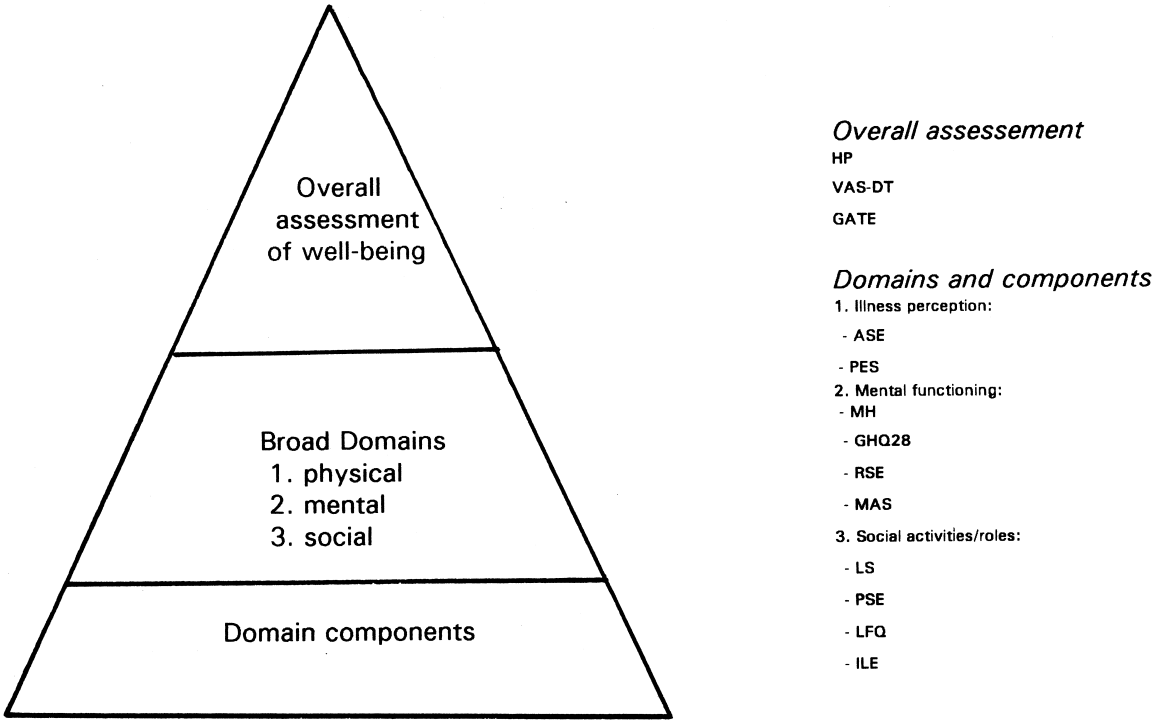

Figure 2. *Levels of quality of life and accompanying measures.*

disease-*related* they are not disease-*specific* (i.e., only applicable to a specific disease).

In Figure 2, the three QoL levels are presented in combination with the accompanying measures we used in our research. Table 3 gives further information about these instruments: full name of measure, format, range of scores, and interpretation of scores.

To assess the individual's *general health perceptions,* we used three measures. Six items were selected form the MOS-SF20 (39); these six items appeared to constitute a hierarchical scale measuring one's health perceptions (HP) (40). In addition, a visual analogue scale with ''delighted-terrible faces'' (VAS-DT) was used in order to assess the patient's valuation of his QoL (41,42). Also, one item was added to assess one's appraisal of the ''general adjustment to epilepsy'' (GATE): ''Do you think that you have adjusted well to the situation and can cope well with problems that have developed as a consequence of epilepsy?'' As part of a larger set of items measuring the ''subjective definition of an illness,'' a similar item was used in two other research projects of which the first author is project leader (one among RA patients and one among MS patients).[†] Another item from this latter set of items was also used in our study in order to measure the ''appraisal of the severity of epilepsy'' (ASE): ''Epilepsy is a sever disease.'' Notice that the term ''epilepsy'' in these items can easily be replaced by any other label. This item was intended to measure the *''physical domain''* of QoL together with five items measuring ''perception epilepsy seizures'' (PES). These items came mainly from the QOLIE-89 (18,42). The *''mental domain''* was assessed by means of well-validated instruments: the 28-item version of the ''General Health Questionnaire'' (GHQ28) (45–47) measuring psychological distress, the ''Rosenberg Self-Esteem'' scale (RSE) (48), and the Mastery scale (MAS) (49). In addition, five items from the MOS-SF20 (39) assessing ''mental health'' (MH), were used; these items appeared to constitute a hierarchical scale (40). Finally, the *''social domain.''* This was measured by the loneliness scale (LS) (50,51). This is an 11-item Rasch scale assessing the subjective experience of an unpleasant or inadmissible lack of (quality of) certain social relations. A phenomenon often mentioned in relationship to epilepsy is stigma that is assumed to affect the

[†] Part of the results of the multiple sclerosis project were published in 1997 (43). A description of the project on rheumatism was presented in 1990 (44). Based on the data of this latter project, many articles and two Ph.D. theses have been published (e.g., see references 47, 64–66). Several other Ph.D. theses are being prepared. Further information both about these projects and publications can be obtained from the first author.

Table 3. *Overview of quality of life measures by level and dimension*

	Scale	Format	Range of Scores	Interpretation
Health perception	Health perception (HP)	Health perception, six statements: absolutely true to absolutely not true	6–31	Higher score indicates better perceived health
	Visual Analogue Scale Delighted-Terrible Faces (VAS-DT)	Rating of QoL, one statement using ''delighted-terrible'' faces	0–10	Higher score indicates better perceived QoL
	General Adjustment To Epilepsy (GATE)	One statement: not at all to very good	1–5	Higher score indicates better adjustment
Illness perceptions	Appraisal Severity Epilepsy (ASE)	One statement: strongly agree to strongly disagree	1–5	Higher score indicates perceiving epilepsy as a more serious condition
	Perception Epilepsy Seizures (PES)	Five statements: very worried to not at all worried and definite to not at all	5–22	Higher score indicates less worry
Mental functioning	Mental Health (MH)	Mental health, five statements: always to never	5–30	Higher score indicates better perceived mental health
	General Health Questionnaire (GHQ28)	Four subscales with each seven statements: not at all to much more than usual	Per subscale 0–21; total scale score: 0–84	Higher score indicates less psychological well-being (or more distress)
	Mastery (MAS)	Seven statements: strongly agree to strongly disagree	7–28	Higher score indicates higher level of mastery
	Rosenberg Self-Esteem (RSE)	10 statements: strongly agree to strongly disagree	10–40	Higher score indicates higher level of self-esteem
Social funtioning	Loneliness Scale (LS)	11 statements: strongly agree to strongly disagree, dichotomized: lonely and not lonely	0–11	Higher score indicates less feelings of loneliness
	Perceived Stigma Epilepsy (PSE)	Six statements: strongly agree to strongly disagree	6–24	Higher score indicates stronger feelings of stigmatisation
	Life Fulfillment Questionnaire (LFQ)	20 statements: very important to not at all important, 20 statements: yes/no	−60–60	Higher score indicates more life fulfillment
	Independent Living in Epilepsy (ILE)	Two statements: strongly agree to strongly disagree	2–10	Higher score indicates stronger feelings of independence

social position and social relations of people being stigmatized. We measured stigma using the ''perception stigma epilepsy'' (PSE) scale (52). The PSE comprises items referring to both ''enacted'' and ''felt'' stigma (53). Life fulfillment was assessed by the ''life fulfillment questionnaire'' (LFQ), an instrument developed by Collings (33,54–56). This questionnaire consists of two sets of 20 items covering the following aspects of daily life: family life, friends, social support, leisure activities, living arrangements, material security, and employment. To yield an LFQ score, a method was used similar to the method developed by Krupinski (57). Respondents first rated the importance they attached to these various aspects of life irrespective of their own circumstances (first set of 20 items), and then indicated whether or not each aspect was true of their own actual life situation (second set of 20 items). Next, the first and second ratings were multiplied by each other to yield fulfillment scores. These fulfillment scores refer to a mental incongruency (i.e., a discrepancy between desire and reality and it is assumed that such a discrepancy causes less social well-being—and probably less psychological well-being too). Finally, two items were added measuring feelings of independence in relations with other people and it was called ''Independent Living in Epilepsy'' (ILE). These items also came from the RA research and MS research mentioned earlier. An item example is: ''People with epilepsy are able to do things equally well as compared to other people.'' These latter items resemble the mastery items but they are specifically focused on the appraisal of epilepsy in terms of independence and have been formulated in terms of behavior.

As far as appropriate, we first calculated reliability figures for all measures (factors or scales) by using Cronbach's alpha (α) (58).

Next, we constructed a *QoL profile* based on all these measures (item, factor, or subscale). To this end we used a procedure similar to the one followed with the Sickness Impact Profile (SIP) (22). First, the scores of each measure were recoded in such a way that for all measures the lowest score was zero. Next, per measure, a mean sum score was calculated and divided by the maximum possible score; this ratio was multiplied by 100. In fact, this score is the percentage of the maximum score. In this way we got standardized scores for each measure running from 0 to 100 with the lower scores referring to worse QoL and the higher scores to better QoL.

Finally, in order to construct a more overall QoL measure, an explorative higher-order principal component analysis (PCA) with orthogonal and oblique rotations according to the varimax and oblimin criterium was carried out. All the analyses were conducted with SPSS/PC + V5.0.2 (59).

Table 4. *Range, scale mean, standard deviation, and Cronbach's alpha of QoL measures*

	Range	Scale mean	sd	Cronbach's alpha [α]
HP	6–31	23.97	5.12	0.80
VAS-DT	0–10	7.57	1.80	OI
GATE	1–5	4.26	0.87	OI
ASE	1–5	2.94	1.40	OI
PES	5–22	16.08	3.53	0.71
MH	5–30	22.01	4.14	0.78
GHQdep	0–21	2.10	3.61	0.88
GHQa&i	0–21	5.25	4.49	0.86
GHQsd	0–21	7.08	2.73	0.83
GHQsom	0–21	5.70	4.16	0.81
GHQ28	0–84	20.14	12.19	0.93
RSE	10–40	30.12	4.67	0.86
MAS	7–28	20.33	3.27	0.75
LS	0–11	6.82	2.98	0.82
PSE	6–24	12.93	3.24	0.62
LFQ	−60–+60	19.24	15.02	0.68
ILE	2–10	7.23	2.27	0.62

OI, one item.

Results

Quality of Life Profile

First of all, reliability coefficients [Cronbach's alpha (α)] have been calculated as far as appropriate. In Table 4 these alphas are presented together with the range, mean, and standard deviation of these measures. Most Cronbach's alphas appeared to be acceptable (≥.60), satisfactory (≥.70), or good (≥.80).‡

Next, for each scale or measure, we calculated the mean score and transformed them all, according to the procedure described earlier, into scores that ran from 0–100. Then, a QoL-profile for the group as a whole could be made (Fig. 3).

From this profile it appears that the QoL of our

‡ Helmstadter (60) considers a reliability coefficient ≥ 0.50 sufficient to evaluate group accomplishments. Nunally (61) and Nunnally and Bernstein (62) recommend a coefficient of 0.70 or above. These values are often encountered in the literature. Based on our own experience, we chose a threshold value of ≥ 0.60.

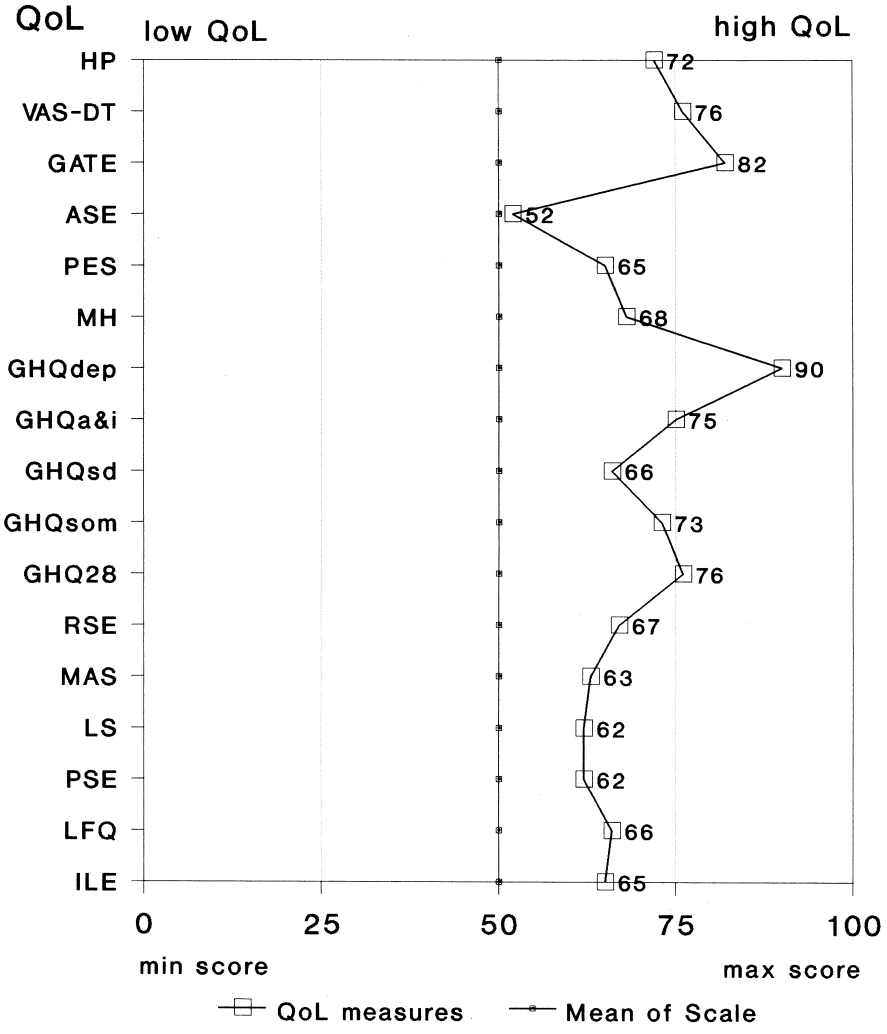

Figure 3. *Profile QoL Epilepsy.*

respondents always lay above the scale midpoint (i.e., above 50% of the maximum score that could be reached on a particular measure). However, this does not mean that their QoL is good or as good as that of healthy persons, or that it is similar to that of people with another chronic disease. At the moment, it would go too far to go into detail in this respect, but, for example, compared to the Dutch adult population, our respondents felt more lonely and could, according to a series of reference values presented by König-Zahn et al. (63), be classified as ''moderate lonely.'' Furthermore, they experienced only slightly less distress than a cross-sectional sample of people with MS (43) and about the same degree as a sample of people with RA with a recent onset (0–4 years). In this latter study, mean scores expressed as the percentage of the maximum score were: 76, 75, and 73, respectively (64–66). However, this latter (RA) group scored significantly worse as compared to a group of healthy controls (mean score: 80). Self-esteem appeared to be about the same for the three groups of patients (mean scores: 67, 65, and 64, respectively). However, 57% reported a very satisfactory QoL that is comparable to 52% satisfied people found in the total adult Dutch population (35). As compared to other groups of people with epilepsy our sample felt quite well. For example, only 4.5% of our respondents considered their QoL as unsatisfactory (i.e., chose a ''terrible face'') as contrasted to 15% found in a large research in the United States (67). Baker and Jacoby (68) reported 63% of their epilepsy research group who chose a ''happy face'' to rate their satisfaction with life. In our study this figure was 90%.

In order to find ''…some agreed statistic which could form the basis for comparison…,'' Cummins (69) compared QoL research outcomes of more than 1000 books and articles that (1) were scanned for

normative data on QoL and (2) met a set of definite methodological, statistic, and sampling criteria. This resulted in 17 normative data sets (with a diversity of QoL-scales) that fulfilled all of the normative criteria. Based on this study he hypothesized a range of 75 ± 2.5%, a value that he proposed as a sort of ''gold standard'' in order to evaluate the level of QoL of specific groups.

Looking at the mean scores of the various QoL aspects measured in our research, it appears that 10 out of 17 scores were below this gold standard; four of them (ASE, PES, PSE, and ILE) explicitly referred to epilepsy itself (cf. Measures and Analyses section). Furthermore, on five aspects, the scores were within the hypothesized range while two exceeded the proposed upper limit. However, from the overall evaluation our respondents gave of their QoL (as assessed by the VAS-DT), it appeared that this ''clinical global impression'' (20) was within the proposed ''gold standard limits.''

Our findings are rather well in accordance with those Cummins (69) found among 55 selected data sets (population subgroups). Selection was based on medical, psychiatric, of sociodemographic criteria. Many of the mean QoL scores of these selected subgroups lied around two standard deviations above or below the ''normative mean'' (=proposed ''gold standard'' of QoL). As far as medical chronic conditions were concerned, the mean scores of these subgroups lied four standard deviations *below* the ''normative mean.'' For physically disabled subgroups this figure was approximately two standard deviations.

Underlying Quality of Life Dimensions

Almost all 13 QoL measures correlated significantly with each other, which partly can be considered as a ''validating procedure'' (''concurrent validity''): 11 were not statistically significant (mostly those with the ''ASE), 53 correlation coefficients were from .20–.50, and 14 were .50 or higher. Our correlation matrix suggested the existence of at least one more general overall QoL-dimension that would be in agreement with Collings' last study in the United States (56). In this study, he constructed an overall QoL-index from the QoL measures he used. Therefore, we carried out an exploratory ''second-order'' PCA on these 13 measures. The results are presented in Table 5.

All measures loaded high on the first factor suggesting *one underlying dimension:* the OQOLI. This is confirmed by the scree plot of the eigenvalues of the extracted factors (Fig. 4).

Table 5. *Second-order factor analysis (principal components analysis): Overall Quality of Life Index (OWOLI)*

Item/Scale	Loadings[a] Factor I
HP	.76
VAS-DT	.68
GATE	.68
ASE	−.22
PES	.67
MH	.75
GHQ28	−.73
RSE	.75
MAS	.79
LS	.64
PSE	−.57
LFQ	.69
ILE	.49
Explained variance	44%
Cronbach's alpha	.90

[a]Loadings >.40 underlined.

There is a very *clear elbow* in the curve of consecutive eigenvalues, suggesting the existence of one general underlying QoL-factor (70). A further rotation according to the varimax criterium did not reveal very clearly a simple structure of two factors (Table 6), which again probably justifies the acceptance of one latent QoL-dimension, underlying our QoL-measures.

However, some instruments loaded clearly higher on the first and some others on the second factor. Therefore, in order to look for two more separated factors, we repeated the rotation proce-

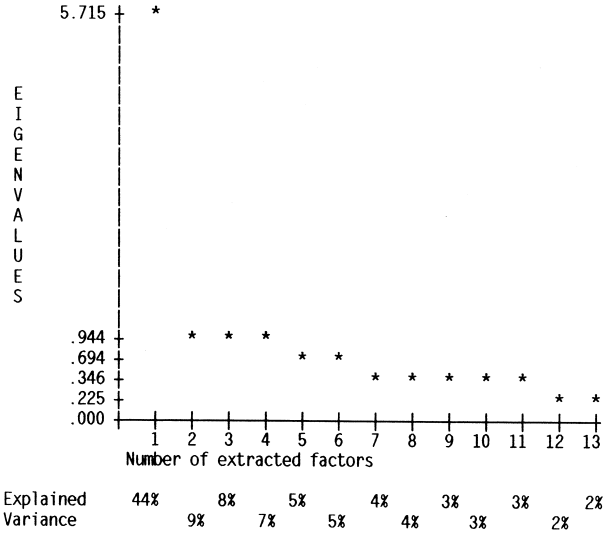

Figure 4. *Second-order principal components analysis: scree plot eigenvalues.*

Table 6. *Second-order factor analysis: orthogonal rotation (varimax)*

Item/Scale	Loadings[a] Factor I	Loadings[a] Factor II
HP	.50	.53
VAS-DT	.79	.12
GATE	.44	.52
ASE	−.04	−.07
PSE	.58	.26
MH	.80	.27
GHQ28	−.80	−.19
RSE	.59	.49
MAS	.60	.51
LS	.35	.60
PSE	−.22	−.60
LFQ	.31	.72
ILE	−.04	.76
Explained variance	28%	24%
Cronbach's apha	.88	.85

[a]Loadings >.40 underlined.

dure but now replaced the orthogonal rotation by an oblique one (Table 7).

As compared to the orthogonal procedure, now much more clearly two factors could be distinguished: our QoL-measures loaded more clearly on either the first or the second factor. Considering the content of the measures that loaded highest on either factor, the first factor seems to refer to ''*psycho–physical health perceptions*'' (Cronbach's alpha = .88) and the second to ''*psycho–social appraisal of epilepsy*'' (Cronbach's alpha = .82).

When we standardize the scores as before, scores running again from 0–100, and divide the scores into four equal categories (0–25, 26–50, 51–75, and 76–100), then it appears that none of our respondents fell into the lowest category, while the second, third, and fourth contained 9%, 63%, and 28% of our respondents, respectively. The mean is 66.9 (sd = 11.6, minimum score = 32.4, maximum score = 90.1), which is below the hypothesized ''gold standard'' range of 75 ± 2.5%, referred to earlier (69).

Discussion and Conclusions

From a series of already existing QoL measures covering the domains of QoL distinguished by Spilker (20), we constructed a multidimensional QoL profile of our group of persons with epilepsy. From this profile it appeared that for many people with epilepsy, their QoL was ''fairly good.'' Compared to other chronically ill groups they often showed similar or higher levels of QoL. However, their situation differed markedly from the healthy population with respect to educational level and employment status, which in the so-called ''social indicators research'' are considered as ''objective QoL indicators'' (1). It is generally assumed that these ''objective indicators'' are conducive to QoL on the individual level. However, it should be noticed that these kind of comparisons must be treated cautiously because of differences between samples concerning sampling procedures and sample bases. This may cause large differences with respect to the composition of the various groups under study, for example, with respect to duration and onset of the disease, and demographic characteristics such as age and sex. Moreover, one should not only take the scale means into account but possible differences in standard deviations between groups as well.

In this context, one further remark should be made as to the possible consequences of the sampling procedures used in our study. As stated earlier, our research group comprised a large number of people with partial epilepsy. Besides technologic (diagnostic) innovations we believe that this may be mainly attributed to our sampling procedures: sample base and enrollment procedures. The sample base consisted largely of patients from ''third echelon'' outpatient clinics of a special epilepsy center, while only patients who had an appointment with their specialist were asked to participate in our study. Both these aspects of our sampling proce-

Table 7. *Second-order factor analysis: oblique rotation*

Item/Scale	Loadings[a] Factor I	Loadings[a] Factor II
HP	.40	−.44
VAS-DT	.85	.10
GATE	.34	−.46
ASE	−.04	−.01
PES	.57	.10
MH	.80	−.08
GHQ28	−.83	−.02
RSE	.51	−.39
MAS	.51	−.40
LS	.21	−.58
PSE	−.06	.60
LFQ	.12	−.72
ILE	−.27	−.85
Explained variance	25%	21%
Cronbach's alpha	.88	.82

[a]Loadings >.40 underlined.

dures may have biased our sample in medical and/or psychosocial respects (i.e., patients with more medical and/or psychosocial problems may have been enrolled into our study). A further indication of this may be found in the large percentage of respondents who were a member of the Dutch patient organization for people with epilepsy (EVN), which is much higher than the one found in the total population (30% versus 3%–4%). However, although we realize that our results may not be generalized to the total epilepsy population, the biased character of our sample may make our QoL data even more promising. After all, it may be expected that in less biased, more representative samples, QoL will even be better (i.e., will be more similar to that of the healthy population).

Twelve of the 13 QoL measures we used in our study, appeared to constitute one single QoL-dimension underlying these measures. A further analysis using PCA with oblique rotation yielded two factors with one factor referring to ''*psycho–physical health perceptions*'' and the second to ''*psychosocial appraisal of epilepsy*.'' The advantage of such higher-order factors is that they ''…have often proved useful in summarizing the results of large analyses that produced many factors'' (62). Consequently, it allows for a more simple communication of the information.

Some additional remarks should be made. First of all, it should be noted that an oblique factor solution may be somewhat more difficult to interpret than an orthogonal rotation. But according to Nunnally (61) there is no decisive reason to refrain from oblique rotation. Both procedures ''…lead to essentially the same conclusions about the number and kinds of factors'' (62). Second, the two oblique factors only explained a little bit more of the variance than the first factor found in the PC analysis and less than the two factors after orthogonal rotation. Third, the loadings on the first factor of the PC-analysis as well as the scree plot of the consecutive eigenvalues of the PC-analysis suggested the existence of one latent QoL dimension.[§] For these reasons one might be slightly in favour of one factor. However, in addition, and in support of the oblique two-factor solution, when primarily is looked at the highest loadings on the two orthogonal factors acquired after the orthogonal varimax-rotation, we must add that the orthogonal two-factor solution encountered, was very similar to the oblique two-factor solution, therefore, supporting the idea of two QoL-factors. This can be seen as a valid reason to use the two separate factors instead of only the first principal component.

As discussed earlier, in our study no QoL measures were developed de novo. Instead, already existing, mostly generic QoL-measures were used. The main reasons to propose such a procedure were of theoretical, comparative, and resource-optimizing nature. After all, the QoL construct was introduced to assess and evaluate more comprehensively the outcomes or effects of medical interventions. However, in view of theoretical modeling (i.e., when one is primarily interested in the interrelations between the various aspects of QoL), the QoL concept should be unfolded into its components and hypothetically related to each other. This is what has been proposed in models such as those presented by Pope and Tarlov (30) and Verbrugge and Jette (71). Our analyses seem to support the feasibility and usefulness of such an approach.

A chronic illness may disturb someone's life in many respects, which is referred to before as ''illness intrusiveness.'' Because of a loss of resources it places the affected people in a disadvantaged position with respect to the achievement of valued goals and interests (8,12,72). Therefore, a loss of resources because of, for example, a chronic illness may stimulate people to adapt, which implies: a shift of means, standards, and goals giving the affected people the opportunity to regain a sufficient satisfactory level of well-being as defined by these people themselves. This may also partly be interpreted as a reduction of mental incongruence (73) between the actual situation and the desired situation. These processes will probably be more effective in the psychosocial than in the physical domain of daily functioning. From our discussion on a ''noncategorical approach'' as well as from a recent publication of Kempen et al. (74), the picture emerges that mental health was the least affected by a series of chronic medical conditions while physical symptoms ''…accounted for relatively high proportions of the variance in HRQL.'' Therefore, although their QoL may have changed according to ''objective parameters'' (e.g., employment, education, physical functioning), after a process of adaptation people may come to define their lives again as ''satisfying.'' That seemed to be the case for the majority of our respondents, a conclusion that is in agreement

[§] The factor correlation between our two factors is .494. Nunnally and Bernstein (62) recommend that when in exploratory analysis the correlation is $\geq .50$, replacement of the two factors with one should be considered. This will reduce the dimensionality of the solution, often with little reduction in fit. A correlation of $\geq .70$ would be a very strong reason to do so.

with the findings and interpretations of Cassileth et al. (26), Collings (33,54), and Cummins (69). Further analysis of the patterns underlying these dynamic processes deserves our further attention as is further comparative and longitudinal research across diseases, including epilepsy, and countries in which QoL should be conceived as a ''…socially constructed phenomenon that must be addressed by increasing opportunities for self-determination in terms of both skill development and environmental support'' (75).

Further analyses relating socio–demographic and clinical variables to QoL and exploring and explaining the interrelations between the various components of QoL will be subject of further publications and research.

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